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**“It Takes a Village”: A Qualitative Analysis of Black Women’s Experiences Navigating
Healthcare with High-Risk Perinatal Conditions**

A thesis presented by
Simileoluwa Elizabeth Falako

to

the Yale University School of Public Health
In Partial Fulfillment of the Requirements for the
Degree of Master of Public Health in the Department of Social and Behavioral Sciences

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Secondary Advisor and Principal Investigator: Oluwatosin Adeyemo, MD, MPH

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Abstract

Black women have a likelihood of maternal mortality that is three to four times higher than white women in the United States. In Connecticut, most pregnancy-related deaths are from Black and Latinx women, even though they do not have the majority of live births in the state. This study aims to explore the medical experiences of Black women with high-risk perinatal conditions and their navigation of healthcare at a tertiary care center in Connecticut. A qualitative study was conducted using semi-structured interviews with seven Black women with hypertension and/or diabetes in pregnancy who gave birth at a large, tertiary medical center in Connecticut between July 2020 to September 2021. Participants' diagnoses included gestational diabetes mellitus, type II diabetes mellitus, chronic hypertension, and preeclampsia. Participants were offered a \$25 gift card for their participation. Data analysis involved coding using deductive and inductive approaches for the transcribed interviews. Descriptive statistical analysis of quantifiable chart data was also conducted. Seven key themes were identified and organized based on the individual, interpersonal, and institutional factors that shaped participants' navigation of the health care system as Black, pregnant women: 1) impact of personal background on healthcare navigation, 2) effect of support systems on healthcare navigation, 3) limited flexibility with clinic appointments, 4) health system resources improving healthcare navigation and disease management, 5) reliance on online resources to determine points of care, 6) role of the provider in patient understanding, and 7) provider interactions that disrupted continuity of care. Participants had overall positive experiences throughout their pregnancy, but some noted areas for improvement to better their perceptions of care. Our findings will help provide specific measures for healthcare providers and hospital administration to improve the quality of healthcare for Black mothers in the state of Connecticut and beyond.

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Table of Contents

ABSTRACT	2
ACKNOWLEDGMENTS	3
1. INTRODUCTION	5
1.1 BACKGROUND	5
1.2 LITERATURE REVIEW	6
1.3 MATERNAL HEALTH IN CONNECTICUT	8
1.4 SIGNIFICANCE OF THE STUDY	9
1.5 RESEARCHER POSITIONALITY	10
2. METHODS	11
2.1 STUDY OVERVIEW	11
2.2 SAMPLING RECRUITMENT AND DATA COLLECTION	12
2.3 DATA ANALYSIS	13
2.4 ETHICAL CONSIDERATIONS	14
3. RESULTS	16
3.1 PARTICIPANT CHARACTERISTICS	16
3.2 QUALITATIVE FINDINGS	18
4. DISCUSSION	40
5. CONCLUSION	45
REFERENCES	47
APPENDIX	50

1. Introduction

1.1 Background

Maternal mortality is defined as the death of a woman “while pregnant or within one year of the end of pregnancy from any cause related to the pregnancy (PMSS, 2020).” Since maternal mortality itself is a general risk for women of all racial and socioeconomic backgrounds, the disproportionate mortality of Black mothers is often easily concealed under the guise of genetics and personal lifestyle choices, however, there are components rooted in racism and discrimination—key social determinants of health (Greenwood et. al., 2020).

Studies show that in the United States, which boasts of having one of the most innovative health systems in high-income countries, Black women have a likelihood of maternal mortality that is three to four times higher than white women (Roeder, 2019). Moreover, more than 50 percent of maternal deaths and near-deaths in the U.S. are completely preventable, and a large proportion of these preventable deaths are from Black women (Roeder, 2019). Many of these preventable deaths occur due to high-risk conditions during pregnancy, such as preeclampsia, cardiomyopathy, and hemorrhage. A pre-existing diagnosis of diabetes mellitus, a condition in which the body’s ability to produce or react to insulin is impaired, can greatly impact a mother’s ability to give birth without any complications. Furthermore, gestational diabetes mellitus (GDM), diabetes that is diagnosed during pregnancy and resolves after delivery can increase the likelihood of fetal macrosomia as well as increase the risk of hypertension (Mayo Clinic, 2022). Hypertension, diagnosed before or during one’s pregnancy, may contribute to the development of preeclampsia. Preeclampsia, characterized by elevated blood pressure as well as symptoms with or without laboratory abnormalities that signal impact on end organs, is a dangerous condition that develops after 20 weeks of pregnancy and can be potentially fatal. Non-Hispanic

Black women have been found to have five times the rates of preeclampsia and eclampsia in comparison to non-Hispanic white women (MacDorman et. al., 2021). Additionally, non-Hispanic Black women are 63% more likely to have diabetes compared with non-Hispanic white women (MacDorman et. al., 2021). These high-risk conditions disproportionately impact Black women across their lifespan and greatly contribute to disparities in maternal health outcomes. However, few policies or interventions address the inequities affecting Black maternal health (Mead et.al., 2008).

1.2 Literature Review

Unfortunately, such inequities are not new and are partly rooted in historical mistreatment of Black women in the US. From 1845 to 1849, J. Marion Sims, the father of gynecology, practiced several experimental procedures on enslaved women, with the “promise” of curing their ailments (Sims, 1884). Anarcha Westcott, one of the ten enslaved women in Dr. Sims’ care, was operated on without the administration of anesthesia, even though anesthetics became readily available in 1846 (Domonoske, 2018). Dr. Sims performed over thirty operations on women like Anarcha in the name of scientific advancement, without consent and regard for their autonomy and well-being. Despite Anarcha’s forced, yet considerable contribution to the development of surgical interventions for vesicovaginal fistulas, her name was rarely mentioned by Sims and is rarely recognized in the medical community. Furthermore, from the 1920s to the 1980s, doctors in the South would perform “Mississippi appendectomies” in which physicians would perform non-consensual, secret sterilizations of poor Black women who entered hospitals for completely unrelated surgeries (Kluchin, 2011). Women who refused to be sterilized were threatened with the removal of their welfare benefits, forcing them to finally concede to

treatment. The US Supreme Court's justification for the sterilization of Black women in 1927 was based on assumptions they were "too promiscuous" and "feeble-minded" to bear children further strengthened the stereotypes of Black women as overly sexual and lacking in autonomy to make their own decisions about their bodies (Cohen, 2017).

The effects of such unethical medical practices and racial indignities continue to the present day. A 2019 study that examined the effects of skin tone on delayed prenatal care found that women who self-identified as the darkest ends of the pigmentation continuum reported more instances of racial microaggressions and were associated with the highest rate of delayed prenatal care (Slaughter-Acey et. al., 2019). Additionally, further studies reported that doctors have been found to "disregard or downplay Black patients' complaints of pain", leading them to administer weaker medication or otherwise withheld treatment (Eligon & Burch, 2020). These false stereotypes that characterize Black individuals as having a higher pain threshold in addition to the idea that Black patients are less compliant have disastrous consequences for the quantity and quality of medical care they receive (Miller & Kaiser, 2001). Moreover, organizational policies at clinics and hospitals that "flag" and separate some patient records and subsequent clinic treatment from others based on condition status, also work to perpetuate problematic stereotypes of individuals and can potentially subject them to lower-quality care (Nyblade et. al., 2019). These institutional practices worsen the stigma against Black individuals and contribute to false narratives of Black mothers that lead to increased morbidity and mortality.

While it is true that increased maternal morbidity and mortality can be linked to lower educational attainment or socioeconomic status (SES), many of the health disparities in maternal health as it pertains to Black women persist even when controlling for differences in SES and education (Howell, 2018; Decelerq & Zephyrin, 2020). Reports show that Black women report

some of the highest rates of microaggression in clinical settings, with one study citing that 22 percent of Black women experience some form of discrimination when going to the doctor (National Partnership for Women & Families, 2018). This discrimination manifests in many ways from implicit biases to perpetuating racialized stereotypes regarding Black pain. This indicates that special attention must be taken to both personal, interpersonal, and institutional spheres to eliminate these inequities.

To address this, it is important to accurately assess and better understand the effect of discrimination on maternal health outcomes. Current investigations often rely on hospital or health department data to determine the prevalence of maternal and infant mortality among Black women; however, this data can sometimes be inconsistent in the amount of detail and limited in quality. For the past 30 years, the Centers for Disease Control and Prevention (CDC) has tracked the rates of pregnancy-related deaths through the Pregnancy Mortality Surveillance System (PMSS), and while the available data has made clear trends in overall mortality, as well as mortality by race, there is limited data available that can account for the reasons behind the increasing prevalence of black maternal mortality (PMSS, 2020).

1.3 Maternal Health in Connecticut

Furthermore, maternal mortality and morbidity tracking can vary from state to state. In Connecticut, it is reported that while 64% of pregnancy-related deaths were of Black and Latinx women from 2015 to 2017, they only account for 45% of live births in the state (Kosutic, 2020). Despite this startling disparity, data on racial disparities in pregnancy-related deaths are either not available or extremely limited for Connecticut (Kosutic, 2020). Efforts were made by the state of Connecticut to reference disparities in maternal and child health outcomes through the

creation of the Connecticut Maternal Mortality Review Program in the early 2000s and the Connecticut Maternal Mortality Review Committee in 2018 (Kosutic, 2020). However, these initiatives do not include the voices of mothers in Connecticut, but rather they include health providers, social workers, and community health workers that are part of organizations for psychiatric disabilities or substance use disorders (Kosutic, 2020). Given this, it is crucial to learn about the experiences of mothers in Connecticut to identify determinants of racial disparities in maternal health.

1.4 Significance of the Study

This study is motivated by the need to identify factors that impact the health outcomes and quality of care for Black women with high-risk pregnancy conditions in Connecticut. Learning from the experiences of mothers who gave birth in hospitals can provide necessary insight into developing evidence-based care to improve maternal health outcomes (Vedam et. al., 2019; Declerq et. al., 2014). This emphasizes how hospital systems may be uniquely positioned to improve the standard of care for Black women throughout the state, especially those with pregnancies complicated by medical conditions.

The primary aim of this thesis is to explore the experiences of Black women with high-risk perinatal conditions and to evaluate how individual, institutional, and interpersonal factors shaped their navigation of healthcare services throughout pregnancy. It seeks to address the following research questions: How does Black identity shape how pregnant women with high-risk perinatal conditions such as hypertension and diabetes receive healthcare? How does knowledge of Black maternal mortality impact the understanding of how diabetes and/or hypertension impact their pregnancy? What resources did Black mothers find helpful or

unhelpful during pregnancy? What role can providers play in the delivery of culturally sensitive maternal and child healthcare?

1.5 Researcher Positionality

S.F is a first-generation low-income Black, Nigerian-American woman. Born in the Midwestern United States, S.F recognizes that the geographic location and culture where she spent most of her life may be quite different from the East Coast. S.F shares many of the same identities as the Black women interviewed in this study. However, S.F recognize that my experiences may be different from those of the participants that were interviewed, and she takes great care to ensure that all stories are uplifted and recognized. S.F is extremely passionate about Black maternal health because of how it could personally affect her and those who share the same or similar identities. Furthermore, she takes great care in understanding those who have differing identities, as personal identity can greatly change how one navigates their health and wellbeing in the healthcare system. O.A, the principal investigator of the larger study, is a Black, Nigerian woman and is a practicing board-certified obstetrician-gynecologist with training in qualitative methodology.

2. Methods

2.1 Study Overview

As part of the larger, ongoing Black Maternal Health Study, we are using a mixed-methods approach to explore the experiences of Black women who are 6 weeks to 1 year postpartum with known high-risk disease conditions of diabetes and/or hypertension in pregnancy. The focus of this thesis was to better understand the patient, provider, and hospital-level factors that impact health disparities in maternal morbidity and mortality. Therefore, the focus of this thesis was on evaluating the factors that impact how Black women perceive their navigation of the health care system.

This thesis utilized qualitative research methods with a grounded theory approach in order to understand the experiences of Black women who delivered a baby at a tertiary health care center in Connecticut. The participants in the study had conditions of diabetes and/or hypertension during pregnancy and were at increased risk for pregnancy complications. Through semi-structured interviews, participants were asked about their lived experiences and interactions with health care providers during pregnancy, labor, and delivery, and postpartum.

To capture the diversity of pregnancy experiences, we recruited participants through a variety of approaches including social media outreach and hospital care communication. Historically, when examining previous studies on Black maternal health in the United States, they have only referenced “Black or African-Americans”, rather than investigating the experiences of Black women from other cultural backgrounds (Almeida et al., 2013; Green 2012). In order to capture immigrant and first-generation mothers' experiences that are often overlooked, we recruited participants with various cultural backgrounds. Gaining greater insight into the care needs, expectations of care, and knowledge of health and healthcare navigation, was

critical to our study aim of understanding the perceptions of Black mothers who had diagnoses related to hypertension and diabetes in pregnancy.

2.2 Sampling Recruitment and Data Collection

To be eligible for study participation, individuals had to meet the following criteria: self-identified as Black (African, African-American, Afro-Caribbean, and/or Afro-Latinx), be at least 18 years of age, be six weeks to one year postpartum, given birth at the selected tertiary hospital in Connecticut, and have a history of medically diagnosed diabetes and/or high blood pressure during pregnancy or in the postpartum period.

Participants were recruited via Facebook, Instagram, the study website, word of mouth, EPIC in-basket messaging, and paper flyers posted around the city where the hospital was located. We also held recruitment meetings and communicated with the community organizations via email to raise awareness about the Black Maternal Health Study to support recruitment efforts.

Additionally, clinical members of our research team conducted outreach among colleagues that served mothers who would meet our eligibility criteria, requesting they share details of the Black Maternal Health Study with potentially interested patients. The research team also made posts on Facebook in hopes of targeting mothers located in Connecticut and mothers who primarily identified as Black immigrants located on the East coast of the United States. Running, paid advertisements on Instagram and Facebook were also used for recruitment. Interested potential participants were encouraged to contact members of the research team via email or phone for a pre-screening interview. Once participants were determined eligible for participation, a study team member scheduled a time to review the consent form over the phone

and obtain verbal consent. A copy of the consent form was emailed to participants ahead of the call for their review. Each participant provided verbal consent granting the research team permission to access their electronic medical records (EMR).

After obtaining consent, O.A., the principal investigator of this study and a practicing board-certified obstetrician-gynecologist, reviewed the participant's EMR to further confirm medical diagnoses and study eligibility. After this secondary screening, the research team re-confirmed the participant's interest in taking part in the study and schedule the 60-minute study interview. All interviews were conducted using the Zoom audio-video platform due to social distancing guidelines spurred by the COVID-19 pandemic. Of the thirteen participants who expressed interest in taking part in the study: seven completed the interview, two were scheduled to participate but did not show up to the interview, one did not provide consent for the EMR review, and three did not qualify for the study. This left us with a sample size of seven participants.

Participants were re-consented at the beginning of each interview to ensure they understood the study procedures and agreed to be audio-recorded via Zoom. Participants were compensated with a \$25 Amazon gift card for their time and participation. Upon completing an interview, the interviewer wrote a one-page memo to summarize the key points of each interview. All interview audio files were transcribed for further analysis using Trint software.

2.3 Data Analysis

We adopted a grounded theory approach to analyze our qualitative interviews (Corbin and Strauss, 2014). After de-identification of the transcripts, one study member S.F coded the transcripts using Dedoose software and developed a codebook. Deductive and inductive methods

were used throughout the data analysis process. Based on literature and clinical expertise, S.F determined codes that would need to be applied to all transcripts, including but not limited to perceptions of disease impact on baby, medication usage, and symptoms during pregnancy. In addition to this deductive approach to coding, we further analyzed the interview data using an open, or inductive coding technique, developing codes from the data as we read through each transcript. The interviewer's written memos at the close of each interview were also used to support the creation of codes. Study team member O.A reviewed the transcripts and codes developed by S.F for internal consistency. The final codebook for this thesis was developed and agreed upon by both S.F and O.A. S.F reviewed the memos written by interviewers (S.F and O.A, read the full transcript and excerpts, and examined all the codes that were relevant to healthcare navigation and provider-patient interactions to identify seven themes related to navigation of the health care system. Additionally, O.A and S.F met to discuss both code application and healthcare navigation themes.

2.4 Ethical Considerations

IRB approval for the study was granted by Yale University. Because the interviews had the potential to bring up sensitive and confidential topics that may have been emotionally uncomfortable for participants, we determined this to be of minimal risk to participants. Therefore, participants were allowed to decline to answer any questions that made them uncomfortable and were allowed to stop the interview at any time. An informed consent form was sent to participants ahead of their scheduled interview and re-consenting was done at the time of the interview to inform them of the research study's background and objectives, anticipated or potential risks associated with study participation, compensation, and participant

rights. Each participant consented to have their interview recorded via Zoom and was compensated for their participation at the end of the interview.

3. Results

3.1 Participant Characteristics

Our final study sample consisted of seven women: five of which identified as African-American and two identified as Afro-Caribbean (Table 1). Two mothers had chronic hypertension before becoming pregnant, two mothers had chronic hypertension diagnosed in pregnancy, two had preeclampsia (one of which was diagnosed postpartum), two had gestational diabetes, and one had a pre-existing diagnosis of type 2 diabetes before becoming pregnant. Some participants had multiple high-risk diagnoses: one had hypertension and Type 2 diabetes, one had hypertension and gestational diabetes, and one had hypertension and preeclampsia. All participants were 30 years of age or older, with five of the seven participants meeting the medical definition of advanced maternal age. The majority of participants had deliveries via Cesarean section. Most participants identified themselves as married. All participants had some post-secondary education, with the majority having a graduate degree. All participants were medically insured, and Connecticut Medicaid was the most common insurance type amongst participants.

Table 1: Participant Demographics (N=7)

	Number (%)
Ethnicity	
African-American	5 (71.4)
Afro-Caribbean	2 (28.6)
*Disease Condition	
Gestational Diabetes Mellitus	2 (28.6)
Type II Diabetes Mellitus	1 (14.3)
Chronic Hypertension	4 (57.1)
Preeclampsia	2 (28.6)
Insurance Coverage	
Husky (CT Medicaid)	4 (57.1)
Private	3 (42.9)
Multiparous	
Yes	5 (71.4)
No	2 (28.6)
Age at Time of Interview	
30-34	2 (28.6)
35+	5 (71.4)
Method of Delivery	
C-section	5 (71.4)
Vaginal	2 (28.6)
Marital Status	
Single	3 (42.9)
Married	4 (57.1)
Education Level	
Some College	2 (28.6)
Bachelor's Degree	1 (14.3)
Graduate Degree	4 (57.1)

* Some participants have more than one condition.

3.2 Qualitative Findings

Seven key themes were identified as characterizing Black mothers' experience navigating the healthcare system during pregnancy. The themes were organized across three major categories: individual (participants' background), institutional (hospitals and clinics), and interpersonal (interactions between the patient and provider). Specific themes include: 1) impact of personal background on healthcare navigation, 2) effect of support systems on healthcare navigation, 3) limited flexibility with clinic appointments, 4) health system resources improving healthcare navigation and disease management, 5) reliance on online resources to determine points of care, 6) role of the provider in patient understanding of high-risk pregnancy management, and 7) provider interactions that disrupted continuity of care.

3.2.1 Individual Factors

3.2.1.1 Impact of Personal Background on Health Care Navigation

Personal background can play an important role in how mothers perceive and interact with the healthcare system. One participant described how her race and age affected her view of health,

"... Being a black woman, I know the disadvantages you have, especially with high blood pressure and being older. It really had me looking like I need to change this because not only am I having another child, but I'm also still a mother. And I didn't want anything bad happening now. Like, it really was a drastic thing for me, like my diet changed. And even with that it still [rose] and I had to go on bed rest." - Participant 1

This participant discussed how her circumstances, particularly her race, served as an indicator of "disadvantage" and why she felt more motivated to control her hypertension. Furthermore, her fear of adverse outcomes for herself and her child seems to be attributed to her knowledge of how Black identity is regarded in the health care space. In addition to personal feelings, a

participant mentioned how her conversations about pregnancy with other people center on the knowledge of her race. One participant mentioned,

“You tell someone you're black when you're pregnant and they want to tell you about like maternal death statistics for black women. You're like, really? I guess. I know, but but can you stop? I think people think they're being helpful in that moment. And it's like, please don't tell me how how all these other black women in my position die during this. Not not right now.”-
Participant 4

For this participant, hearing stories of death and tragedy for Black women did not serve as a supportive space during her pregnancy. A participant with mixed heritage shared,

“... My mother's white and my father's black and just knowing my mother's side of the family, women my age who actually have babies had nothing wrong with them. But then compared to all the black women that I know health wise, it was like one person had a stroke that I know...and that played a part from her blood pressure. So, it really scared me because knowing my African-American heritage takes over more than anything, you know, it is scary. Scary.” – Participant 1

This quote describes a personal account of the witnessed differences in outcome for white and Black mothers in the participant's family. The participant's family history shaped her perception of how her race could have a greater influence on the outcome of her pregnancy in comparison to other important aspects of care (i.e., medication use, prenatal visits, and adherence). In addition to family history, some participants talked about how their past experiences made them more cognizant of how to navigate the system while pregnant. This participant noted,

“So just knowing and reading about... like the disparity in like health care and a few things well, a lot of black women, not just black, but minority women don't necessarily have access to a lot of, you know...health care, right? Good health care, let's say, and affordable health care, let's say. So, there's just disparities in that, but then also me as a black woman having gone to... Like I remember vividly a doctor before I might have been like in my late teens, maybe I think I was like in my 20s, like in college, phasing out of college. I remember distinctly going to my primary and saying, Hey, I feel X, Y and Z going on with me, you know, I feel whatever it was, I don't

recall. um. And she kind of like pooh-poohed me to the side, like almost like, oh, there's nothing wrong with you, oh, there's you know what I mean? Instead of doing blood work instead of doing urinalysis instead of, you know, like really digging deep into or, you know, entertaining what I was saying. So, I know that there's a lot of that too, like just really not listening to women who, you know, they know they've been living with their bodies for however long. So, they kind of know or should know. But I know a lot of people in the medical field don't necessarily listen or take black women seriously in that way. Yeah. So just knowing that going into it, you know, but me, I'm, you know, somewhat educated and I am a great historian of my health, I am. So, I will, and I advocate, I know how to self-advocate.” – Participant 7

This quote describes how the participant’s awareness of Black maternal health outcomes along with her past experiences with her primary care provider shaped how she perceived the quality of her healthcare. Her description of feeling dismissed by her previous primary care doctor highlights how often Black women can be made to feel that they are incapable of understanding their bodies. For this participant, such experiences of being dismissed made her recognize the importance of speaking up for herself while pregnant, especially in a health care space where the consequences of being dismissed could put her as well as her unborn child at risk. Another participant similarly explained the importance of self-advocacy in her pregnancy journey,

*“I'm also pretty diligent right to my one of my first couple of visits at *****, my weight got tracked wrong by 20 pounds. I read and I wrote them and I said, this is wrong. Like I'm reading my after-summary visit. It's right, you know, and I see stuff that's incorrect. And I think I corrected them like twice about stuff that was in there that was wrong. So, I'm generally pretty diligent about that kind of thing, which personally, I think really impacted the quality of my care. I also have like a very strong working understanding of like medical terms and have like a lot of friends who are doctors and nurses, labor and delivery, things like that. But I also read on the Internet. Right. I also like to stop and ask people like, what do you mean by that, and they don't have a problem doing that. Honestly, having that kind of rapport did, I think, increased my quality of care. I bet you can very easily be railroaded in those environments. I feel like people feel pretty disempowered. I think particularly black women. I felt very empowered. But I also sort of established that I follow up, I check, you know, and I think that helps quite a bit.”- Participant 4*

In this quote, the participant described having to take extra measures to ensure that the circumstances surrounding her care were as accurate as possible. Reading through summaries and exercising more diligence improved her impression of the quality of healthcare she received. These extra tasks help facilitate closer patient-provider relationships even in a busy environment like a hospital, which can also contribute to improved care. However, it is important to note that such tasks can also put extra strain on patients and that there are limitations of self-advocacy for mothers who may not have the knowledge or resources to identify their care needs. Additionally, this participant also detailed a default sense of disempowerment for Black women that seem to be alleviated when self-advocacy is practiced. Another component was how research surrounding one's racial background shaped the perception of treatment. One participant noted,

"I read articles before I became pregnant about how African-American women were treated in the health care. I just was wondering, like, I wonder if other races were treated differently. So I felt like I could have been treated a little bit better....It definitely opened my eyes to see like how they would treat me just like even waiting in a waiting room and stuff.....There was the instance where I was walking to the back for my stress test and another patient was with me and the nurse was more like talking to the other patient and kind of like ignored me, just escorted me to my room and she said, like, really very minimum to me. And then she had like a full-on conversation with this other person. And I just explained to my provider things that, you know, I needed. Like as far as me telling her that I had carpal tunnel on my hands and she just like "Okay, cut your salt intake." I felt like she didn't really care about my health. Like, I had to wait for other appointments to another provider to provide me with hand brace for my hands and a belly brace for me."- Participant 6

This participant's experience emphasizes how previous knowledge of disparities and mistreatment of Black women in health care may have generated a keen sense of awareness of possibly being treated differently. This participant's perceptions about her communication with the nurse and her experience going to another doctor to receive care may present issues for Black moms, especially for those who must attend more appointments. One participant summed up her personal experience being Black and having preeclampsia as,

“I just feel well, you know, yes, I identify as Black, and I feel like going through this experience... With preeclampsia, it really opened my eyes to what the health care system and just advocating pretty much you have to advocate for yourself and that's what pretty much me and my family talked about after my experience, that you just really have to look at some more things and you have to ask more questions and you have to hold your your physicians accountable. With certain things, but that's just the culture of my family pretty much.” – Participant 5

The emphasis on self-advocacy throughout this participant’s pregnancy journey indicates how much race relations may have set a precedent in how participants viewed their healthcare and navigated the healthcare system, particularly when dealing with an acute or chronic condition. The described “culture” of accountability and advocacy amongst participants is likely a result of instances where self-advocacy increased the quality of care, they were able to receive whereas lack of self-advocacy left them wanting or expecting more from their health care providers.

Overall, personal circumstances and experiences surrounding race generated an increased awareness of one’s long-term health, instances of perceived biased treatment, and self-advocacy among participants. In this way, participants’ backgrounds and past experiences, particularly concerning their identity as Black women in the United States played a significant role in how they navigated the healthcare system during pregnancy and perceived the care they received.

3.2.1.2 Effect of Support systems on Healthcare Navigation

The role of support on Black women’s maternal health experience was another key theme. Participants overwhelmingly noted that support systems during pregnancy provided a source of comfort and ease while navigating the healthcare systems. When asked to describe her sources of support, one participant mentioned,

“Like I said, it takes a village. So, my village literally swarmed in to help me, you know. My mom has helped me. I have my cousin who comes to help. My village and my house. My village just come in to help whenever they can. And I feel that that's definitely cultural, that's a cultural thing. Cultural and familial.” – Participant 3

The description of the family unit as a “village” by this participant is a demonstration of how relatives served as a resource for this new mother. For those with difficulties in pregnancy, the presence of family served as additional support and helped in providing informal health information specific to both maternal and infant well-being. Many participants discussed how they turned to family and friends with their maternal health-related questions and emphasized how this played a major role in their pregnancy. One participant noted,

“My aunt is she's a R.N. And then my mom because she's a diabetic, so she will kind of check up like, did you take your sugar today? Did you prick your finger? How do you feel? It's nice to have that support. Definitely. Because like, I'm normally I work a lot, so sometimes I tend to forget. So, they have that phone call, like, did you check? It helps. It was very nice to have that support.” – Participant 6

The family background and history helped this participant stay accountable for disease management during their pregnancy journey. This is especially important for Black women with high-risk conditions that need to take extra measures while pregnant. Additionally, having medical professionals as a source of support outside of her regular provider contributed to filling in information gaps for participants. In addition to having family with a medical expertise and experience navigating care, other participants had their families play other important roles throughout the pregnancy journey. This participant mentioned,

“I mean, like everyone in my family is college educated and like many of them are nurses or doctors, and so I feel like I was surrounded with really good information. My husband is from Haiti. He's Haitian. He had very different cultural perceptions about pregnancy care and delivery and stuff like that, not not good, bad, or indifferent. Just just different.” – Participant 4

This participant describes how she came from a family that has a strong educational background and is healthcare-oriented which helped her gain more knowledge about her pregnancy. This quote also describes how different cultures can shape how one perceives the whole pregnancy journey. Her husband's Haitian culture is distinct from the prevailing belief in western contexts. The two differences between their culture and the United States highlighted by this participant suggested that cultural differences can impact the maternal experience throughout pregnancy.

Support networks further filled gaps in care in situations where the clinic was not immediately available. This participant noted,

“.... My back was really, really hurt on one side and I'm like, oh wow. And that at that time, I was still calling the maternal fetal triage hotline number. Nobody answered again. So, I told my husband he was like, maybe tell the baby's nurse, and I'm like, what? That's the baby's nurse. What is what is she going to do, you know? And he was just like, you never know. So, we go back upstairs, and he was like, are you going to tell her?..... I told her what was going on and how I couldn't get a hold of the triage. And she was just like I think you should go to the E.R. and I'm like, oh, you know, I don't know. And she was just like, no, I think you should go. In matter of fact, I'm going to have somebody watch the baby and I'm gonna bring you downstairs. And then, lo and behold, I had multiple pulmonary embolisms in both lungs, and I had pulmonary infarction. So, one of my lungs, part of one of my lungs, basically died.”- Participant 7

This situation is an example of how familial and provider support during pregnancy could help mothers advocate for themselves as they navigate the healthcare system. In this case, when the hospital hotline put in place for high-risk mothers was temporarily unavailable, the husband's encouragement coupled with the nurse's support galvanized the participant to communicate how she felt, which led to a diagnosis of a severe condition. Thus, the presence of family can assist with the mothers' self-advocacy efforts.

While awareness and support from family members made the navigation process much easier for some, family dynamics also played a role in mothers becoming more resilient in the difficult processes of navigating care. One participant expressed,

“Yes.... I guess that I was drawing on the strength of my ancestors, so to speak. Like I said, my grandmother had nine children. I have an aunt who had 18 children. My grandmother had nine children, I think, and only two of them were born in a hospital. So, I took all that, like, you know, I don't have any right to complain. I have all these modern luxuries, things that people don't have. If she could do it nine times, the third time is not going to kill me. So, I just I took I drew I drew that strength from those who have gone before me. They'll do it after me.” – Participant 3

Having a support system with an extensive history of birth and motherhood, as stated in this quote, demonstrates how the experiences of those within one's close social networks can influence their understanding of healthcare, making women feel better prepared to tackle issues that could potentially arise throughout pregnancy. At the same time, this strength and resilience can also mask important issues due to the resignation that they should have “no right to complain” as the participant highlighted in her quote. This may mean that she may not express issues she has during her pregnancy because of her family's past. Overall, this form of familial support served to help moms better navigate the health system as well as improve management of their high-risk conditions.

3.2.2 Institutional Factors

3.2.2.1 Resources Provided by the Health System that Improved Healthcare Navigation and Disease Management

The hospital and clinic environments that participants accessed for care throughout pregnancy have their own set of organizational facilitators and barriers to healthcare navigation. In order to address issues that came up during pregnancy, participants noted receiving various

resources provided by the hospital that served as a facilitator in supporting pregnancy and high-risk conditions. One of the key physical resources that helped moms were blood pressure monitors, which first started being distributed during the pandemic to assist with telemedicine appointments. One participant diagnosed with preeclampsia mentioned,

*“My blood pressure was managed through blood pressure cuff; I was given a blood pressure cuff upon discharge from the hospital they gave me. They entered me into a study, a **** study conducted by pharmacists. So, they gave me a blood pressure cuff and they put me on medication called nifedipine. I was at 60 milligrams. And then later I went down to 30 milligrams, and I will take one pill per day. As for what they wanted me to do with it, after I took my pill, take my blood pressure and document it on the MyChart site.”- Participant 5*

This quote exemplifies how a patient was able to have a better understanding of her condition and medication management when given a blood pressure monitor. This use of the monitor to document the effect of nifedipine on the participant’s blood pressure measurements is a key example of how hospital resources served to facilitate disease management and navigation of hospital resources. However, it is important to note that during the COVID-19 pandemic, blood pressure monitors were provided to some patients for them to use during telehealth appointments. Another physical resource given to a participant was a continuous glucose monitor (CGM). A participant with type II diabetes and chronic hypertension described,

“So, they got me the CGM. They did what they needed to do with insurance to get it, get it for me. And that really, I mean, the medical device was a real game changer in terms of how I generally manage it. And I stopped doing fingerstick. So, I really only do fingerstick to calibrate my CGM.”- Participant 4

The same participant also relayed,

“OK, so now I'm learning a little bit. So, like when I'm breast feeding and/or pumping my blood sugar, I actually just tend to drop kind of equivalent to like a workout. So, I'm kind of learning to the CGM is showing me exactly how that activity is happening. So, I have had more lows than I had before pregnancy, even though I'm taking less medicine because I am nursing or pumping, you know, 10, 12 times a day. So, I do now.”- Participant 4

The quote shows how hospital providers worked with the insurance to provide an essential resource for this participant. Having an instrument that would measure the participant's blood glucose made it easier for her to manage her condition by reducing the number of fingersticks she had to do. The use of instruments to minimize the less comfortable aspects of high-risk disease management and increase awareness of their condition daily.

Beyond medical instruments, participants were also given paper resources to inform them of different points of their pregnancy. One participant noted,

“They give me a little book about what to do after I have the baby and how to care for my incisions and stuff like that, but that was it and they talked to me about it a little bit. The book was helpful because it just gave me like a breakdown of like certain things. So, the book was helpful. I still have it. I still kind of like, look through it because I'm also breastfeeding. So, it gave me tips on breastfeeding and stuff.”—Participant 6

The participant felt that this book served as a resource even after her pregnancy, supporting her efforts to breastfeed. She also found the resource book to be informative in understanding how to care for herself and her baby during the postpartum period. Another participant used pamphlets given by the clinic as a key source of information stating,

“They gave me a lot of pamphlets. Any any questions that I may have had for them, they answer them. They will come pretty much come to the appointments, ready to discuss certain topics. So, they were pretty resourceful.”— Participant 5

Furthermore, the same participant relayed,

“With the information they gave me and after I started researching it on my own, it kind of came together, their information.... and from what I understood, so it helped a lot more when I put everything together, I wasn't completely clear on the development of what preeclampsia was before I found out.”— Participant 5

Pamphlets, a popular resource given to pregnant patients, helped this participant supplement her research and form important questions to be later answered by her provider. The combination of the pamphlets with the ability to clarify any confusing information served as a guide in this participant's navigation to better understand her condition.

Another resource supported by the hospital that made participants comfortable was alternative medicine practices. One participant mentioned,

*“When our child was breach, we used homeopathic methods, we use spinning babies, we used Chinese herbal tactics, but **** did provide me and say, hey, we don't have any evidence of this, but give this a try. And I said, OK, great, we tried them. It worked. Right, perfect. Right. We're not here sort of shunning things like that.... Someone said this worked for [me], someone said it didn't work for me. But the same can be said for any Western medicine. Some people's bodies are receptive to something, some peoples are not.” – Participant 4*

This quote demonstrates how the institution's flexibility and openness to the use of alternative practices to alleviate complications in pregnancy helped the participant not only be receptive to different treatments but also use the hospital as a resource for different types of care. The hospital's provision of resources that may not be as commonplace and are more culturally diverse may serve to facilitate better care for pregnant mothers.

3.2.2.2 Limited Flexibility with Clinic Appointments

Pregnant women with hypertension and/or diabetes, are high-risk and have to attend more prenatal appointments throughout their pregnancy in comparison to mothers who are not considered high-risk. This reality as experienced by participants in our study allowed a unique insight into the challenges that can present when navigating the need to schedule and attend more frequent appointments. A participant diagnosed with both gestational diabetes and hypertension mentioned,

“The wait killed me. The wait was very frustrating, and because it was just like, they want you to be at appointments at say, like 9 a.m. and then you're not seen until like 9:45 or 10 o'clock or 10:15. So for me, it was frustrating.” – Participant 6

While many situations may necessitate a patient's appointments being delayed, this experience may be very difficult for participants who have work or caregiving responsibilities. Additionally, another participant noted that in addition to the delay she experienced at the clinic, there appeared to be limited flexibility in scheduling, despite the complexity of her situation. One participant stated,

“I think the scheduling, like I think for somebody like me who had like twice weekly NSTs, I made it such that I was on Monday and Thursday. Every week, same time, and I, for something like that where it's like you're going to be doing this through the end of your pregnancy, letting people block out, I don't know.... If they just let me block, like, weeks at a time. Like, I have all my appointments blocked for a whole month. It's like let people just go in and pick their times and block them. Like, let me go ahead and schedule my own time, like, why are we playing this game of well, do you have.... OK, well who do you have that? No, just say these are the NST times and go in and book your times. There's a real reluctance to, like, give people the power to do that themselves. I don't know what's going on there.” – Participant 4

This quote described that despite the frequency of the non-stress tests she had to attend, the participant felt it was difficult to have appointments that fit her schedule. The participant noted that the back-and-forth nature of scheduling can be frustrating especially when mothers have other obligations, for example, work, childcare, etc. Her suggestion of blocking weeks at a time for appointments may be a way for hospital administration and patients to work together to meet the needs of both entities. Another participant further expressed difficulties with scheduling regarding childcare,

“And also, like my son was schooling from home. So, like I had I needed to bring him places with me. And that was difficult because he wasn't allowed to come with me there. ---Well, his dad helped me out a lot. And then my boyfriend, when he was here, they would keep him OK. And I did have some appointments that I wasn't able to go to because at the time my boyfriend wasn't

here, or his dad wasn't able to take him. So, I had to just cancel, and they just gave me another date that they had.”- Participant 2

This quote demonstrates how navigating her prenatal appointments were made more difficult because of her difficulty in obtaining childcare. Because the mom was unable to leave her child with a caregiver, she had to miss some appointments. The same participant mentioned that,

“In the clinic itself... No, there weren't [resources]. Especially when I was like, I need to see my doctor, but, you know, my son's with me. He's only five. Like, I did all of that. And they're like, I'm sorry, you can't come in. We'll just call you to reschedule. And I'm like, oh, that sucks. So not really.” – Participant 2

Considering the patient reported that the clinic did not provide childcare resources, this may have made it difficult to come to all scheduled appointments. It is important to note that the clinic did offer alternate times to schedule appointments, but the participant's hardship in finding childcare could continue to serve as an obstacle to care. Another instance of scheduling difficulties was when a participant had concerns about circumstances surrounding her delivery,

“And I was like I don't know if my boyfriend is even going to make it here to be here with me. So that was like my biggest concern. And they were just like, well, we're going to schedule it, and I was like, OK, can we schedule it for 40 weeks then? And they're like, no, we usually schedule at thirty-nine, especially because he was, he was a big baby. And I'm like, oh my God, you guys are just not listening to me, but. So, I felt like they could have probably. I don't know, even if they knew I needed to have a C-section, just encourage me more for or act like you supported my decision at least, but they were just like they were not even hearing me about having a [VBAC]. Mm hmm. But they were supposed to be like I, you know, a doctor or agency that's supposed to support [VBAC]. But it didn't feel like it at all.”- Participant 2

Despite her reservations about 1) her partner not being present for the birth and 2) having a Cesarean section (C-section), the participant seemingly accepted why it was indicated but did not feel the hospital acknowledged or addressed her concerns which led to increased fear and hesitation. Her experience and sentiments emphasize the need for medical centers and health

providers to better balance the need to provide quality, safe, and appropriate care with strong person-centered care and communication, particularly in high-stress situations.

3.2.3 Interpersonal Factors

3.2.3.1 Reliance on Online Resources to Determine Points of Care

In addition to institutional factors, participants emphasized the importance of the relationship between the patient and healthcare provider. For participants to be able to assess the care they need (apart from what was communicated by the provider), they often relied on online resources to determine what they perceived to be best for themselves and their baby. When asked for the reasons why she conducted outside research, one participant said,

“Because I felt like, you know, a lot of my appointments were just like short. And I felt like I know how I feel, but I don't think they know how I feel because they're just coming in, they're just checking the heartbeat, checking the the lungs, and they're like, OK, we're good. How is your ...? Look, I'm looking at your test, especially like when I had to do the sugar to the... It was just like, OK, your test scores look like they're normalizing, that's good. And I'm that like that was it like there was nothing else. And I'm just like, well, I feel this. Let me Google that. And I feel like this, and I feel like that. And I'm like, you know, a lot of the way, oh, that's normal. Like even when I asked him a lot of stuff like, oh, that's normal and not really explaining why it's normal. So, I would go online and find out, like, why is it normal? Why do you know, why does it feel like that or why do I feel like that.”— Participant 2

This participant often referred to resources like Google because she felt like it would provide further support for her pregnancy and blood sugar management beyond her regular appointments. Another participant mentioned,

“What helped me understand it was I have previously like I said, I know people that had [high] blood pressure. So that's what helped me the most. And then just literally researching on my own

to have a better understanding. Somebody can tell me something about it and I won't have a clear understanding unless I'm actually reading it and understanding it for myself. So that's what helped me.” – Participant 1

This quote demonstrates how participants did their research to better understand how their condition might affect their pregnancy. Information from personal acquaintances or their providers may have not always been enough to solidify their understanding of how to best take care of themselves throughout pregnancy or manage their disease. The use of online resources appeared to be used as a source of self-support and helped her to better navigate her healthcare. Specifically, a participant noted how she used online resources to suggest alternate forms of care,

“I don't know, because they scheduled my son to be to have a C-section and be like as soon as they found out I was breach, like and as soon as they knew, OK, she's breech, and she has the gestational diabetes. Let's just go ahead and schedule her the appointment. I'm like now, like, there is, you know, ways that midwives move the baby with their hands. Like, I watched it on YouTube. I well, I Googled it like I know there's other methods of getting the baby to move, but I don't want to just depend on a C-section.”- Participant 2

This participant used the information she learned online to inform how she wanted her delivery to proceed. This demonstrates how critical outside information shaped the interactions between the providers and the patient even in times of high stress, like delivery.

3.2.3.2 Interactions with Providers Disrupting Continuity of Healthcare

One of the most important aspects of perinatal well-being, especially for those with high-risk conditions, is continuity of healthcare. However, some participants experienced negative situations and interactions that made them consider disrupting the care they had with their current provider. One participant recounted,

“I actually wasn't around my blood pressure cuff. And I called and said, if my blood pressure, if I feel certain ways to call them, let them know. So, I called, and she happened to be the one who called me back. And it was "where was your blood pressure cuff?" And I'm like, I'm not home. "Well, you should be home with your blood pressure cuff, like what's wrong with you" and I was just like, excuse you like enough is enough. Like, no, you know if she was like, "that's what's wrong with you now." And I was like, excuse you. It was like such was such taken back with just that one particular person, you know? That if I was somebody else, I'd probably left the practice altogether just because of her, but because I love the practice that I'm in, I love the doctors here, you know, I couldn't allow her one opinion of me or my religion, whatever it had been, you know? Treat that differently.” – Participant 1

This quote was a situation in which the participant felt that a provider did not understand the patient’s circumstances and the participant felt blamed for not knowing her exact blood pressure measurement. The participant felt that this situation would have pushed her to leave the practice, but because of how highly she spoke of other providers in the practice, she decided to stay. The participant detailed another experience with the same provider saying,

“So, because of my religion, she thought that I wouldn't immunize my child. She thought that I wouldn't be on birth control. It was just the assumption she was like, well, because of your religion, you're not going to circumcise your child or you're not going to immunize your child or you're not going to get on birth control afterwards. And I'm like, just because of my religion doesn't mean anything. I'm an individual, you know? And it was like I said, because I was in a different town at the moment, you know. And like I said, I've never missed an appointment. Even if it was just a video chat with them. I never. And come on. "Well, maybe you should find a different doctor" was like, wow, and I said something to the other doctors about it, even the secretary about it, because it's like. Is it because I'm covered? Is it because I'm a Muslim, because I didn't get this before? You know, I've never got that with any of the other doctors. So, I think it was like way out of line. So and so whenever I got an appointment, I made sure that it was never with her....” - Participant 1

The intersectionality between race and religion is important due to how the biases the participant reported related to her being Muslim rather than being Black. The perceived biases toward the participant made an uncomfortable situation, where she felt like she could not meet with the provider again because of how she was perceived. It does appear that even with a provider that

made her feel uncomfortable, she was still able to schedule appointments with providers who made her feel comfortable and continue her care. This also speaks to the benefits of team-based care offered by perinatal and obstetric clinics.

Care encounters during the postpartum period also had a significant impact on participants' overall experience navigating healthcare. One participant did not finish her postpartum appointments due to a negative encounter during a procedure. She mentioned,

“So, I went for my six weeks postpartum, and I didn't even complete. We still haven't completed what I need to do because I think I'm supposed to I was due for a pap smear and I had to do something else, but I think my cervix was really hard, I don't know, but. The doctor was just not not very she wasn't patient, or she wasn't, you know, she was just rough, I thought, and she was just like. Well, we're going to have to reschedule this, because if you're in this much pain, like we're not going to be able to get I pap smear done, I think she was just doing like a STD test or something. I don't remember. And she was just like, I'm going to send you a prescription for something to start off.... like a ball or something to have my cervix soften and I'm just like I'm not even I'm not coming back. You are not nice. Like you are not you're not patient. So, I do need to make that appointment, though, because I do need to have my thing. But I have to, I totally want a different doctor.” – Participant 2

This participant reported that she refused to come back for her postpartum appointment because of the perception that her provider was rougher and more impatient during a procedure. This had the participant feel uncomfortable with coming to another appointment, even though the provider was willing to prescribe something to help with the pain of the procedure. Such experiences demonstrate how one negative encounter may have harmful effects on appropriate follow-up during the postpartum period, which may delay general preventative health services pertinent to women's health. Another participant noted,

“I left early. I signed out early. And I want to say I think I had him on a Sunday, and I think I signed out maybe like on a Tuesday or Wednesday and I was supposed to leave on a Friday... It was just like two people who made my experience very uncomfortable. So, I just was like, you know, I'm going home. I didn't like the fact that one of them just kept coming into a room without being announced. And I know that much like when you come into the room, you are supposed to knock on the door and announce yourself before you come into a patient's room, and she didn't

do that. And then I had another nurse who just like, was complaining about dumb stuff. She was basically telling me how to feed my child. And then she was complaining that the baby peed on her, and I don't know if she meant it in a joking way or not. But when you have a nurse, complain about that one annoyance, it was like in the wee hours of the morning, probably 2:00 in the morning or something. So, this just made my stay uncomfortable, and I just end up leaving.” – Participant 6

This participant expressed that she felt that a few nurses that she interacted with made her feel uncomfortable by not expressing basic courtesy or making her feel unfamiliar with infant care, even though she was an experienced mom. Other participants expressed other uncomfortable situations, including a situation where a participant stated,

“And actually, I should just I should just stop doing it [epidural], because to me, it's like it's a waste, but it takes too long for them to place it. And the last time I felt like they were just playing around, it's always usually like a resident and not the chief attending or something like that. And I feel like they're poking and playing around on my back. I'm in excruciating pain like they're having. I was pissed off because I felt like they were having the whole lesson back there on my back and I'm uncomfortable like I had. So, I guess I just I felt like the epidural did not take. And when I said it to the nurse, I said to my husband, even when I said it to the anesthesiologist, they said it takes some time or, you know, you're still going to feel some you're still going to feel the pressure. And I'm like, I, I didn't feel like that was pressure. I was feeling pain. But because because they were telling me that's what I was that's what I was feeling. I just took it for what it was and went about and just kept going.” – Participant 3

Furthermore, the participant mentioned,

“It probably did invalidate my feelings because they no one believed me, so to speak. But at that point in the moment, I was just concerned with having the baby and just getting this over with.”—3

In this quote, the participant reports that she was in pain, and she felt that her feelings were not being acknowledged. Even while she was in pain and voiced her concern, she felt that she did not have a solid understanding of why the epidural placement was difficult. The participant's feelings of “invalidation” may result in some patients not wanting to continue with a course of treatment, in this specific case using an epidural, because of how they felt in the past.

3.2.3.3 Role of the Provider in Patient Understanding of High-risk Pregnancy Management

Healthcare providers are tasked with playing an important role in helping expecting persons and families understand how their pregnancy is progressing or condition is being managed. Participants in our study described different experiences regarding how their provider shaped their understanding of their high-risk perinatal condition and treatment options. One participant stated,

“So, my doctor came and she was so sweet, you know, like and she was like, I'm so sorry. I got the impression that you came here to do a C-section. I'm very sorry. It was not, you know, communicated to me correctly. She was I can definitely check your cervix. And, you know, she's basically talking to me and my boyfriend about why she thinks I should do a C-section and she would rather do it than having to go through, you know, waste time doing all the tests to only have to do an emergency C section for my health and the baby's health. And that made me feel a lot better. So, she did check my cervix and of course, I wasn't dilated at all. So, you know, you know, she was like, do you want to wait? She's like, if you want to wait a couple of days, we could wait a couple of days, two days max. But I would rather do it now than have to go in through emergency because anything can happen and I'm like, OK. So, I think that, you know, at least she makes me feel like she still tried, and she gave me an option, you know, made me feel a lot better, more comfortable to trust her.” - Participant 2

This participant's experience with a doctor who took the time to explain why it was best to do a C-section really improved the way that the participant viewed the changes in her mode of delivery. Additionally, the doctor giving her an alternative option (while still clearly explaining the risk) increased the participant's trust in her doctor and made her feel less ignored. Another participant who had to undergo induction explained,

“And generally speaking, the Black women that I've encountered in those [Facebook] groups are very anti induction, very anti induction. And I didn't quite see why. My best girlfriend and college roommate was also induced. Loved it, but people are very anti-induction, very anti- C

section. So, I did sort of ask myself, well, I'm going to be induced. I don't see a problem with it. They explained to me why and I said, OK, that seems reasonable.” - Participant 4

The prevailing negative perception of induction and C-section was also partly dispelled by providers taking time to explain why induction would be the best option for the participant's pregnancy. A lack of understanding can lead to these “anti-” opinions, but the role of the provider in calmly explaining what is going on during pregnancy can foster better understanding and communication between patient and provider. Another participant mentioned how her providers shaped her pregnancy journey,

*“Oh, very good. Very good. I had a few. I started out with one OB in a practice and there was multiple OBs in that practice. So, you know, that one wasn't available, I would say, because you never know who would, you know, who you would have at the time of birth, you know who deliver you. So, you know, you've got to know all of them. And they were all very nice and very helpful even on the phone, you know, things like that. So, I got to know them all and I feel as though they were they all and it was all women in that particular practice. It happens to be all women. So, I felt as though they cared and wanted to see me do well. So that's how I thought. And then I had. You know, because I was high risk, I had to be referred out, you know, for consults and things of that nature. But even though I had consulting doctors at ***** still very nice, very nice and, you know, knowledgeable and listened.” – Participant 7*

The feeling of being listened to and having providers that were helpful even beyond the one-on-one appointments made this participant feel like she was being well cared for. Additionally, being able to feel that even while she was high-risk, she felt such treatment made her feel better during the pregnancy journey. Another participant discussed how her doctors helped her understand her hypertension diagnosis,

“Just talking to my doctor, talking to the doctors, because I was in the group, I saw a couple of them. But just talking to the doctors and having a better understanding in charge of trying to get a grasp of what was going on, on the things that I can do to curb the high blood pressure, monitoring my diet, my exercise, stuff like that, just having a better understanding or just having a better overall understanding and education about having high blood pressure in pregnancies. And and now my understanding is I probably have chronic hypertension for the rest of my life. So, we'll see. So, this may be something I'll have to live with continuously throughout my.... throughout my life.” – Participant 3

The understanding of both how she could improve her blood pressure during her pregnancy and how it would impact her long-term health is extremely important for providers to make sure their patient is aware. The direct conversations between the participant and her providers bolstered her knowledge of her condition and shaped how she would continue to navigate her health.

On the other hand, some participants expressed a lack of understanding even with a provider they could reach out to. One participant mentioned,

“I would have liked them to inform me more about the gestational diabetes the first time that I took it. I had a lot of swelling, too, that I also talked to them about, and they were just like, oh, that's normal at this time of pregnancy, a lot of females, they you know, they swell for different reasons. Just give me I don't know if there's anything preventative about it. I didn't really look it up, but just tell me some stuff that I could have probably done to prevent having all those swellings, because that made it painful for me to do stuff, too.” – Participant 2

While different parts of pregnancy are considered normal, providers explaining away this participant's concerns about her swelling and pain did not contribute to the participant's understanding of her pregnancy and her gestational diabetes. Furthermore, the fact that the participant did not feel as if she had the right preventative resources or information from her providers made it more difficult to navigate her healthcare. Not only does this lack of understanding impact understanding of one's overall condition, but also more specific instances in the doctor's office. This participant noted,

“Um. I would have felt better if they were kind of... I felt like, I don't know, I felt uncomfortable during one of the procedures. I felt like maybe they could have been a little bit experienced, but then they could have talked a little bit more to me.” – Participant 6

Communication is extremely important in the care of a patient. The patient's feeling of having limited information may affect how the participant understands how the procedure would impact her and her baby. Another participant mentioned another instance where she felt discomfort,

"I don't remember the doctor and I didn't like that. Like I said, I had tore. And they started stitching me up and no one said anything. I literally felt the stitches coming. I felt the stitches like I literally felt the thread going through my skin. And I jumped because I didn't know what was going on, like, oh yeah, maybe we should numb you. And I was like, you think? They didn't numb me. And at that point, they're like, well, you know, if we numb now, like at this point, like, they said they only had like two more stitches. And I was like, oh, this point just keep going."-
Participant 3

The quote again emphasizes the need for better communication between provider and patient to ensure that the patient is aware of the circumstances surrounding her care. The participant's lack of familiarity with the doctors and the physical pain during the procedure caused discomfort and may have contributed to the negative feelings about her patient experience.

The provider plays a critical role in helping the patient understand what is going on at different points of care in their pregnancy. Clear communication and listening to the patient helped participants be more comfortable and build rapport with physicians.

4. Discussion

This research analyzed the individual, institutional, and interpersonal factors that shaped healthcare navigation among Black mothers with hypertension and/or diabetes in pregnancy at a tertiary medical center in Connecticut. The results indicate that there are instances where Black women felt supported and experienced barriers to care in the clinic and hospital.

At an individual level, the knowledge of their predisposing risk factors, racism, and health disparities in Black maternal health, made participants fear or anticipate adverse outcomes for their health due to their racial background. This negative expectation stemming from pre-existing knowledge of the maternal health disparities for Black women as well as pre-existing awareness of medical racism negatively impacts the mental health of Black women throughout their pregnancy and increases the likelihood of experiencing mental distress (Pieterse et. al., 2012). Beyond mental distress that can disrupt overall health in pregnancy, this acute awareness in combination with past negative experiences interacting with the healthcare system can also shape mothers' perception of how they would need to navigate their healthcare while pregnant. Previous studies show that historical disregard for patient autonomy by providers can often reduce patients' engagement during medical encounters (Dutta-Bergman, 2005; Wiltshire et. al., 2006). This demonstrates the importance of alleviating racial/ethnic differences in Black maternal health outcomes as well as improving awareness of providers to understand how their interactions with patients can have a long-term impact on the patient. Another way that personal background affects the navigation of health services is through self-advocacy. In this study, participants mentioned how being able to advocate for themselves greatly improved how they perceived their relationships with providers and the management of their high-risk conditions. Being able to take charge of one's care through self-advocacy can help Black patients to actively

seek health information and be more involved with their health and care (Wiltshire et. al., 2006). Moreover, it is important to note that self-advocacy is positively correlated with the number of resources and information that women have, so support systems, like family who have experience with the disease or work in healthcare, can promote this effort (Wiltshire et. al., 2006; Gage-Bouchard, 2017). However, more research must be conducted to assess how self-advocacy can be increased for Black women as well as the long-term impacts of self-advocacy, as it is both health-promoting but can be burdensome for Black women to continuously have to do.

Regarding institutional factors, health facilities should continue to provide physical resources that are specific to easing the burdens of a high-risk pregnancy to provide more helpful information and paths for better self-management. For example, the provision of blood pressure cuffs and continuous glucose monitors to participants by the health institution played a positive role in their pregnancy and allowed them to be more aware of their high-risk conditions. While the rise in the distribution of home blood pressure monitors to patients was a result of the use of telemedicine during the COVID-19, the positive participant experiences demonstrate the need for blood pressure monitors to be continuously available to women with high-risk conditions, particularly hypertension and preeclampsia (Breux-Shropshire et. al., 2015; Citoni et. al., 2021). Patients' increased awareness of their pregnancy conditions should continue to be encouraged through the delivery and use of these physical resources. Furthermore, a study that provided African American participants with a home blood pressure monitor in combination with culturally sensitive education about blood pressure had a significantly lower systolic blood pressure in comparison to individuals who were just given the monitor (Brennan et. al., 2010). This demonstrates, much like was described in the results, that both physical resources and pamphlets can be particularly helpful with Black moms who have conditions on top of being

pregnant. However, it requires that hospitals and clinics set up measures where they are responsive to the culturally specific needs of patients to make the most impact.

Additionally, some participants noted how hospital administrations' restricted flexibility with scheduling appointments presented as an issue in navigating their care. It is also important to note that the COVID-19 pandemic, which was occurring during the time of participant interviews, severely limited the clinic's freedom to schedule appointments and allow family into the patient room, which may have confounded the experiences of the study participants (Arora et. al., 2020; Boelig et.al., 2020). However, studies conducted before the pandemic show that scheduling problems and lack of childcare contributed to high-risk pregnancy patients missing appointments (Campbell et. al., 2000). Since high-risk pregnancy patients have more prenatal clinic appointments, this study shows opportunities for health systems to continue to work on scheduling patient appointments in ways that optimize the patient's needs and circumstances. This is especially critical considering that patients who reside in more remote areas, lack means of transportation and childcare, and/or workplace security may experience barriers to attending clinic appointments if they cannot have more autonomy over scheduling (Fryer et. al. 2020; Ukoha et. al., 2021). The rise of telehealth since the beginning of the COVID-19 pandemic provides a unique opportunity to help mothers who may have issues making it to in-person visits to ensure they still have time to connect with their providers. Studies have demonstrated that telemedicine visits can lead to similar outcomes as clinic visits, increased patient satisfaction for some pregnancies, and allowed more access to subspecialty care for those in underserved areas, which is particularly important for women with high-risk pregnancies (Ukoha et. al., 2021).

Lastly, when evaluating the interpersonal factors, participants reported very positive interactions between them and their providers. Many expressed that they greatly appreciated the

care they received and noted that the providers played a key role in their understanding and management of their pregnancy and high-risk condition. It is important to note that participants outlined the need to better understand the different points of healthcare, especially in pregnancy. A few participants mentioned having to go to multiple providers because they felt that they were not getting what they needed, while some mentioned not knowing what resources they should have in general. To promote individual advocacy and give Black women a space to fight against inequities in care both providers, institutions, and even community-wide organizations can work together to establish a baseline knowledge of what Black pregnant women should expect to receive in their medical encounters. Along the lines of having multiple providers, instances where participants were able to be familiar with their providers, helped participants feel more comfortable. This may contribute to helping moms be able to voice their needs during their pregnancy journey. Moreover, some of the experiences that Black mothers noted in this study, underscore the importance of more sensitivity and assessment of patients' baseline understanding, especially when providing healthcare for marginalized populations (Matthews et al., 2021). With these efforts, providers can gain the necessary tools in ascertaining a patient's level of understanding and positively contribute to the knowledge and understanding of the patient. The ways that providers can be better equipped to help Black women navigate such an intricate health system include friendliness, respectfulness towards the patient, physician elicitation, and responsiveness to patient concerns and apprehensions (Brashers, Haas, Klinge, & Neidig, 2000; Wicks, 2021).

Though this study has provided necessary insight into the experiences of Black mothers with hypertension and diabetes, there are specific limitations to note. One of the most significant limitations is the sample size of the study. We were only able to recruit seven participants at this

point in the study despite having multiple methods of recruitment. This may be due to the specificity of our study population and the effects of the COVID-19 pandemic on maternity care and access. This small sample size can limit the generalizability of the study results as the experiences may be too specific to the individuals that we were able to recruit.

Another limitation that we discovered is that in regards to the diversity of participant populations, all participants had some form of insurance coverage. Because insurance coverage can significantly determine and shape one's healthcare navigation experience, it would be important to include the experiences of those who may not have access to such. Lastly, this thesis did not draw a comparison between participants' perceptions of healthcare to the information documented in their patient charts. This may make it difficult to ascertain if there were resources or communications that participants were provided that they were not aware of. While the original aim of the study was to combine both quantitative data from participant's electronic medical records in addition to their qualitative data, this thesis only evaluated the experiences of patient care from the perspective of the patients themselves. Further work will be conducted to be able to draw more data from patient charts in order to compare the documented information in the charts and the experiences participants had.

5. Conclusion

Black women with high-risk conditions in pregnancy have frequent interactions with the healthcare system, which provides a unique opportunity to learn and improve upon the experiences they faced. This qualitative study sought to explore the experience and perspectives of Black women with high-risk conditions during pregnancy as they navigated the healthcare system. Findings from this study highlight key personal, institutional, and interpersonal factors that impacted the care and perinatal journey of Black women receiving care from a large, tertiary care medical center. Despite the inability to generalize our findings, our results from this study shed light on how health care providers and medical organizations can improve the quality of care provided to women with high-risk pregnancies. The implications of our work are particularly salient to efforts to address disparities in Black maternal health.

Knowledge of Black maternal health in the United States, personal background, and family support throughout pregnancy influenced how mothers approached navigating the healthcare system. Participants emphasized how these personal factors led them to advocate for themselves in healthcare spaces and to be more involved in healthcare decision-making in hopes to avoid possible negative outcomes for themselves and their babies. With greater knowledge of rights and resources, Black mothers and their support systems have previously been found to have increased confidence in advocating for themselves during pregnancy and birth, and our findings align with this fact (Wicks, 2021). Thus, healthcare institutions must not only continue to utilize the wealth of resources to support healthy pregnancy outcomes but must also provide more varied and non-traditional resources for mothers and families from diverse backgrounds who may or may not be dealing with high-risk perinatal conditions, as they navigate healthcare systems. Ensuring patients have a greater knowledge of their condition and the resources they

can receive from health institutions and providers, can boost the impression of quality healthcare and in the long-term improve maternal health outcomes for Black women.

Furthermore, study findings also aid in understanding the pivotal role of health care providers in the Black maternal health experience. Informed by medical ethics, all interactions with care providers are built on a notion that the patient will be always kept secure, that she will be comfortable, that she will be aware of what is going on with her body, and that she will be able to ask questions and receive information about the procedures and possibilities of labor respectfully. However, this is not always the case, as was evident in our findings and should be addressed. It is important to ensure that patients have the understanding, resources, and ability to express how they feel about their care management and treatment throughout pregnancy. Therefore, further research must be conducted to identify the measures that are most effective at improving the quality of provider care and communication as a means of reducing negative maternal outcomes in the long run. Potential provider strategies include providers outlining the point of care during pregnancy and providing information about local pregnancy support groups, especially considering that there are different levels of knowledge about what maternal care can look like in different countries and communities.

This increased communication and understanding between patients, healthcare providers, and healthcare institutions can help to establish more trusting perceptions of health institutions and build better patient-provider relationships. By understanding the experiences of Black women with high-risk pregnancies as they navigate the complexities of their medical care, points for necessary intervention can be identified and steps can be taken to improve the standard of care and increase equitable outcomes for Black mothers and babies.

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Appendix

Appendix 1: Interview Guide

Introduction:

I will be asking you a series of questions about your experiences in pregnancy. At times, it may seem like I am asking you to repeat some things you said in order to get more details however I want to assure you that I am listening to you.

Interview guide: Exploring the experience of post partum Black women with high- risk conditions in pregnancy:
A mixed methods study

1. I understand you had your baby in (month)? Congratulations! What number baby was that for you?
2. What was your most recent pregnancy like for you?
3. I understand that you have diabetes/ high blood pressure during your recent pregnancy, can you tell me more about that?
4. How was it like going through pregnancy with this high blood pressure/ diabetes?
5. What was your initial response to hearing that you had high blood pressure/ diabetes?
6. So how did hearing about this impact you? Impact your pregnancy? Impact your life?
7. How was your high blood pressure/ diabetes managed in pregnancy? What medications were you on if any? How was it like taking medications if applicable? How was it like checking your finger sticks (if diabetes)?
8. Due to your diagnosis, were you recommended to have more appointments? What types of appointments? How did these appointments impact your life? How was it like getting ultrasounds? How was it like getting non stress tests? How was it managing your appointments? How did this testing impact your life?
9. What was your understanding of how diabetes/high blood pressure could impact your pregnancy? Your personal health?
10. What help or did not help your understanding?
11. What resources were made available to you by the hospital or medical providers (if any) during your pregnancy to address your high blood pressure/ diabetes? Explore role of social workers, care coordinators if any.
12. What was your experience like interacting with your medical providers before giving birth/ clinic? Probe for Nurses? Doctors? Midwives? Front desk?
13. What personal challenges (if any) did you have while you were still pregnant (probe for financial, social challenges)
14. What resources were made available to you by the hospital or medical providers (if any) during your pregnancy to address these challenges? Explore role of social workers, care coordinators if any.

Okay now let's transition and talk more about your labor and birth experience.

15. How was your labor and birth experience?
16. How was it like during labor and birth with high blood pressure/ diabetes?
17. What was your experience like interacting with your medical providers in the hospital when you had your baby? Probe for Nurses? Doctors? Midwives? Residents? Front desk?

Okay now let's transition and talk more about post partum and going home (after you had your baby).

19. What was it like after you had the baby?
20. How was your experience post partum with high blood pressure/ diabetes?
21. What personal challenges (if any) did you have while you post partum (probe for financial, social challenges)
22. What resources were made available to you by the hospital or medical providers (if any) post partum to address these challenges? Explore role of social workers, care coordinators if any.

Okay let's move to further discussion regarding your background

23. I understand that you identify as Black, would you like to share anything about your culture or ethnicity?
24. Did your culture and ethnicity impact your thoughts about your pregnancy, labor, and birth? If so, how?
25. Did your culture and ethnicity impact the care that you received during pregnancy? On labor and birth? Post partum? If so, how?

When thinking about your pregnancy and birth experience overall

25. What was the best part of the care you received during your last pregnancy and birth?
26. What was the worst part of the care you received during your last pregnancy and birth?
27. What would you like to change (if any thing) about the care you received during pregnancy, labor and birth and post partum?
28. What would you like to change (if anything) about the way your (diabetes/ high blood pressure) was managed in pregnancy?

Demographic Questions

29. What do you most identify as (African American, Afro-Caribbean, African, Afro-Latinx, Other (Please specify))?
30. What is your date of birth? (mm/day/year)
31. What is the spelling of your first and last name? Is this the same name you used when you had your most recent baby?
32. What was the date of your last delivery (month, day, year)?
33. What was the method of your last delivery (vaginal or c-section)?
34. Which hospital did you deliver your baby?
35. What is your marital status? (Single married, divorced, separated)?
36. What kind of health insurance did you have during pregnancy?
37. What is your highest level of education?